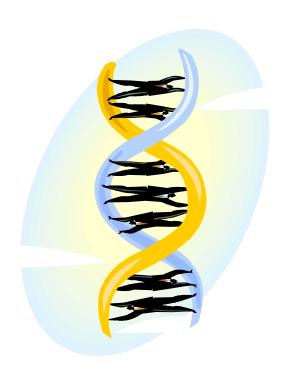
# Genetic Discrimination and Rhode Island Policy

August 27<sup>th</sup>, 2002



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#### I. Introduction

On July 11, 2001, Francis S. Collins, Director of the National Human Genome Research Institute, (NHGRI), testified before a United States Senate subcommittee on the progress of the Human Genome Project. "We can predict that by the year 2010, predictive genetic tests will exist for many common conditions where interventions can alleviate inherited risk; successful gene therapy will be available for a small set of conditions; and primary care providers will be practicing genetic medicine on a daily basis. By the year 2020, gene-based designer drugs are likely to be available for conditions like diabetes, Alzheimer's disease, hypertension and many other disorders; cancer treatment will precisely target the molecular fingerprints of particular tumors; genetic information will be used routinely to give patients appropriate drug therapy; and the diagnosis and treatment of mental illness will be transformed. By the year 2030, we predict that comprehensive, genomics-based health care will become the norm, with individualized preventive medicine and early detection of illnesses for many diseases; and a full computer model of human cells will replace many laboratory experiments."

With the completion of a final draft of the human genome expected next year and the rapid discovery of new genetic tests, it is clear that genetic testing will become more accurate and more commonly used in the near future. This new technology promises great improvements for the public's health, but the potential for misuse is great. The potential for genetic discrimination is greatest within the areas of employment and insurance, as these institutions have a strong economic interest in acquiring genetic information from employees and policyholders. Employers are concerned with productivity and with protecting the safety of their workers, while insurers are concerned with accurate risk classification in order to keep costs down. Already, employers and insurers have used genetic information such as family health-history records to deny employment and insurance, and as the cost of genetic testing comes down, it is foreseeable that employers and insurers may require it.

There is an apparent conflict between the social goods that can be obtained by genetic testing and the individual rights of autonomy and self-determination. Genetic technologies have the potential to vastly improve the overall health of Rhode Islanders and help the Department of Health accomplish its mission, but genetic discrimination threatens to undermine this goal. What is needed is sound public policy that will allow us to achieve the public good that comes from genetic technologies without interference with civil liberties.<sup>2</sup>

According to the State Genetics Plan,<sup>3</sup> it is the responsibility of the Department of Health to take a leadership role in the development of legislation related to genetics. In order to fulfill this responsibility, this document has been written. The sections that follow examine Rhode Island's legislation in the area of genetic discrimination, provide recommendations for additional legislation, and report on the ethical, legal, and social issues that are likely to arise in the future. Section II describes the need for laws protecting against genetic discrimination, discussing existing and perceived discrimination, and the lack of federal legislation. Sections III and IV analyze current Rhode Island law in the respective areas of employment and insurance, and discuss potential uses of genetic information in these areas and alternative policy options. In

section V, a general informed consent policy for genetic testing is considered, that would seek to protect privacy rights and prevent genetic discrimination in areas beyond employment and insurance. There is also an appendix, which lists Rhode Island's laws regarding genetic testing. This report examines legislation in the context of ethical, legal, and social issues, and takes the position that genetic information is unique to other medical information, and therefore deserves special protections against misuse.

# II. The Need for State Legislation

# The Potential for Improving the Public's Health

Genetic testing is an analysis performed on human DNA, RNA, genes, and/or chromosomes to detect heritable or acquired genotypes, mutations, phenotypes, or karyotypes that cause or are likely to cause a specific disease or condition.<sup>4</sup> There are a variety of different kinds of genetic tests that have potential for improving the public health.

Primary Interventions: Diagnostic testing can help confirm a diagnosis for a symptomatic individual, and thus help that individual receive the proper treatment. Predictive genetic testing determines the probability that an individual will develop a condition, and a positive test can indicate an appropriate medical intervention or lifestyle change. An example of this kind of testing involves the BRCA1 and BRCA2 genes, in which mutations can indicate an increased risk of breast cancer. Treatment options include increased surveillance, chemoprevention, and prophylactic surgery. For some genetic conditions such as Huntington's Disease, there is no available treatment, but patients may still be interested in the results of predictive testing for life planning. Carrier testing can determine whether or not an individual is a carrier of an unexpressed trait that may be passed on to children, and thus help individuals with reproductive planning.<sup>5</sup> Another application of genetic testing is Pharmacogenetic testing, which indicates how individuals with certain genotypes will respond to specific medications. Every year more than 100,00 people die from adverse responses to medications, while an estimated 2.2 million experience serious reactions.<sup>6</sup> This form of testing may help prevent many of the illnesses and deaths attributed to adverse responses to medication.

Population Based Interventions: HEALTH has an interest in promoting the utilization of genetic testing for primary care due to the immense potential for improving the public health, but potential applications also include population-based strategies for improving health. Illnesses are the result of a complex interaction between genes, the environment, and behavior. Genetic research will contribute to our understanding of the role that genes play in this complex interaction, and will allow the department to more effectively accomplish the core functions of assessment, policy development, and assurance.<sup>7</sup>

Genetic Epidemiology: This application involves the surveillance of genetic traits in the population. Genetic epidemiology can help the department more accurately determine potential health threats and can be used to tailor interventions to specific populations. Population based genetic screening will allow the department to intervene in cases where early treatment will prevent the onset of a genetic disease. The model for such a program is newborn screening, where tests can only be recommended on the population level when the cost of testing is not excessive, for conditions with a substantially high prevalence, and in cases where early intervention is necessary to improve health outcomes.

Some have already made arguments that population screening should be undertaken for conditions within the adult population. An example is hereditary hemochromatosis, which is treatable, and has an incidence of between 1 in 200 and 1 in 500 for whites. Proponents of adult-

population based screening argue that the major mutation for this disorder can be tested for by a simple and inexpensive mouthwash test.<sup>9</sup>

### Ethical, Legal, and Social Concerns

These potential uses of genetic technology in public health raise a number of ethical concerns. These concerns must be addressed in order to ensure that a) the public is willing to participate in population based programs; b) the public is willing to utilize genetic services in the context of primary care; c) population based programs are effective; and d), genetic discrimination does not encroach upon civil liberties.

Genetic Discrimination: For genetic information to be useful in the area of epidemiology it may need to be identifiable, and there is a risk that third-parties would use such information against individuals. In addition, genetic information tied to racial and ethnic groups could also lead to discrimination against these groups. This was the case in the early 1970's, following Congress' passage of the Sickle-Cell Anemia Control Act in 1972. The sickle-cell trait has a higher incidence in the African American population, and the genetic discrimination which resulted from early screening programs for this disease disproportionately fell upon African Americans. As states began to mandate screening for the sickle-cell trait, several insurance companies began to discriminate against individuals who were only carriers of the sickle cell-trait. In addition, most major airlines in the U.S. grounded or fired employees that carried the sickle-cell trait in the early and mid 1970's, and the U.S. Air Force Academy excluded carriers until a lawsuit was brought against the academy in 1979. These clear-cut cases of genetic discrimination against pilots were justified on the unproven assumption that carriers were less able than non-carriers to withstand the stress of lowered oxygen levels at high altitudes. 12

Stigmitization: If populations at high risk for certain diseases are targeted for more intense interventions, those populations might face social stigmatization and various forms of discrimination not necessarily related to employment or insurance. This problem could be influenced by a lack of genetic literacy in the public. As was the case with early sickle-cell screening programs, people might confuse carrier status or a genetic susceptibility with the actual disease. Social stigmitization is tied closely to genetic discrimination, although it is less overt. In this case, an individual is not necessarily denied a formal opportunity or benefit such as employment or insurance, but may experience more subtle forms of prejudice based on carrier-status, that can make that individual feel like a second-class citizen. A parallel may be drawn here to HIV status. Before the public became educated as to manner in which HIV was transmitted, individuals that tested positive for HIV faced this sort of stigmitization.

*Misinterpretation:* Individuals in low risk groups might misinterpret this classification to mean that they are safe from multi-factorial diseases such as heart disease and cancer, and this could discourage them from practicing healthful behaviors. By the same token, individuals that test positive for certain conditions may believe that they are at a higher risk than they really are. Again, the early sickle-cell screening programs provide an example of this. Early laws did not provide for counseling; and often, individuals that were tested did not understand the difference between the disease and carrier status. As a result, individuals that were merely carriers became needlessly concerned about their health, believing themselves to have the actual disease. 14

Policy Implications: All of these concerns must be addressed before instituting a genetic surveillance program or any population based screening program. The privacy of our citizens must be maintained, and any data collected must remain highly confidential. These protections are necessary in order to ensure voluntary participation in such programs. In addition to creating policy aimed at the confidentiality of genetic information, the public must be educated with respect to genetic technologies to insure that misinterpretation of such information does not lead to genetic discrimination.

#### Public Fears and the Willingness to Utilize Genetic Services

Perceived risk: A 1995 Harris poll of the general public found a high level of concern over genetic discrimination. Over 85% of those surveyed indicated that they were very concerned or somewhat concerned about insurers or employers having access to genetic information, and in a subsequent national telephone survey conducted in 1997; 63% of participants reported that they would not take genetic tests for diseases if health insurers or employers could have access to the results. <sup>15</sup> Studies have shown that whether or not there is any actual risk of genetic discrimination at the hands of employer or insurers, the perceived risk of genetic discrimination is a barrier to genetic services.

In a study conducted by Hall and Rich in 2000, a significant portion of the genetics counselors interviewed, (38 percent), said that discrimination concerns are a major barrier to testing and that large numbers of clients decline testing primarily for this reason. The greatest concern is usually health insurance, although other forms of insurance as well as employment concerns were considered as well. Although the majority of counselors in this study said that these concerns do not have very much actual impact on patients' final decisions about testing, it is important to remember that these patients have already made the conscious decision to schedule an appointment with a genetic counselor. There is no data on the number of people who may not even make it into a counselor's office because of these fears.

Patients who are concerned over genetic discrimination sometimes pay for genetic testing out-of pocket, rather than submit a claim to their health insurance company. Sometimes individuals are so concerned over the misuse of test results, that they will not only pay for testing out-of-pocket, but will send their samples to the testing company under a false name. <sup>17</sup> Genetic counselors as well as patients are concerned over discrimination. In a survey of genetic counselors published in the June 2001 edition of the Journal of Clinical Oncology, an overwhelming majority indicated that they would take a genetic test based on high-risk family history for colon or breast/ovarian cancer, but 68% said they would pay out of pocket for the testing rather than bill their insurer and 26% said they would use an alias. <sup>18</sup>

Although genetic testing holds great promise for improving public health, the possibility of genetic discrimination is a major threat to voluntary participation in genetic research, population screening, and in primary genetics care. Therefore, strong protections against discrimination are needed to ensure that perceived risk does not prevent the public from utilizing genetic services and sharing information in ways that will assist the department in assessment.

Actual Risk: The actual risk of genetic discrimination in employment and insurance is actually quite low. Studies have documented numerous cases of genetic discrimination in employment and insurance, <sup>19</sup> but many of these studies fail to distinguish between discrimination against asymptomatic individuals and those who have already developed a condition. In many of

these cases, a genetic test is used only to confirm a diagnosis. The real concern with genetic discrimination is the case where a perfectly healthy individual who is otherwise employable and insurable will be denied a job or coverage based on the results of a genetic test. Genetic testing is currently too expensive and not accurate enough to be feasible for insurers and employers to require it. Testing for mutations of the BRCA1 and BRCA2 currently costs \$2,760, and far from requiring testing, health insurers often refuse to pay for this expensive test. <sup>20</sup> Even in life insurance, where it might make the most sense for an insurer to use genetic testing, this is rarely done; and is required only for extremely high-risk individuals. Life insurers are able to get similar information without having to pay for expensive and unreliable testing simply by reviewing an applicant's family health-history record. <sup>21</sup>

Although family histories can be used to deny coverage to individuals for certain kinds of insurance, evidence of genetic discrimination based on DNA testing results is anecdotal, and there is no evidence of any widespread or concrete policy of genetic discrimination in employment or insurance. As part of their study, Hall and Rich also conducted a direct market test, in which insurance agents were asked about obtaining individual and group health insurance based on fictitious positive test results for genes such as BRCA1. The study found that even in states where discriminatory practices based on such test results were not prohibited, individuals having positive test results faced little difficulty obtaining coverage. Health insurers have little incentive to use the result of genetic testing in underwriting decisions because most policies last only for several years.

Although genetic discrimination is not currently widespread, it has occurred in rare cases. Insurers and Employers have denied benefits based on genetic information in the past, <sup>23</sup> and genetic discrimination can be expected to increase as the price and predictive power of genetic testing improve. Although insurers rarely request or require genetic testing, they often urge against legislation that would prohibit such practices. They recognize that such techniques may be useful in the future for more accurate risk-classification, and by raising premiums for those predisposed to genetic conditions or by denying them coverage; they will be able to charge lower premiums to those at low risk. For similar reasons regarding cost and predictive power, employers rarely request or require genetic testing at present; but may do so in the future. It is also important to note that genetic discrimination is difficult to prove. An employer is not likely to cite a review of genetic test results of an employee as a reason for termination. Thus, it may be that genetic discrimination occurs to a larger extent than is documented. Public policy is needed to ensure that any uses of genetic testing by employers and insurers, now and in the future, are both fair and respectful of individual rights.

# Federal Legislation

At the present time, federal legislation does little to protect the privacy of genetic information and prevent genetic discrimination. The Health Insurance Portability and Accountability Act of 1996, (HIPAA), is the only federal law that directly addresses the issue of genetic discrimination. It provides certain protections for health insurance, but applies only to employer-based and commercially issued group health insurance. Some have argued that the Americans with Disabilities Act of 1990, (ADA), can be interpreted to protect against genetic discrimination in employment; but it is unlikely that its protections will extend to individuals with unexpressed genetic conditions. There are several bills pending in Congress that seek to

address this issue, but it is unclear how soon Congress will take action; and most of these laws do not provide any additional protections above those already granted by Rhode Island's laws.<sup>24</sup>

HIPAA: This law was passed in order to protect individuals from losing health benefits when changing jobs. Health insurers have traditionally tried to lower costs by denying coverage for pre-existing conditions. HIPAA prohibits group health plans from using pre-existing conditions and genetic information as a basis for denying coverage or raising premiums. HIPAA also prohibits insurers from denying coverage to small employers, guarantees renewability for large and small employers, and prohibits group plans from basing eligibility on an individual's health status, (genetic information being included as a part of health status). It protects an individual from losing coverage during a gap in group health insurance, but provides no protection for those that switch from one individual plan to another, and little protection for those who have not maintained continuous group health coverage. In addition, HIPAA does not prevent employers who offer health coverage from using genetic information to raise premiums, and does not prohibit insurers from disclosing information to other entities.<sup>25, 26</sup>

ADA: The ADA prohibits discrimination against an individual who has previously been disabled, is currently disabled, or who is regarded as being disabled. The ADA is enforced by the Equal Employment Opportunity Commission, (EEOC), which interprets the law as providing protection against genetic discrimination. This interpretation however, is limited in scope and legal effect, and the true protective power of the ADA against genetic discrimination has yet to be decided in court.<sup>27</sup> The concern is that genetic discrimination is different enough from traditional disability discrimination to fall outside of the protections of the ADA. An employer might successfully be able to claim that an individual with a predisposition to a future condition falls outside the jurisdiction of the ADA, because the employer is not regarding the individual as being *currently* impaired.<sup>28</sup> In addition, the ADA's protections do not extend to situations in which an individual's impairment poses a safety threat to others, or in which it is not reasonable to accommodate the impaired individual. Recent decisions have indicated that courts are not sympathetic to the EEOC's interpretation.<sup>29</sup> On June 10, 2002, the United States Supreme Court ruled in favor of Chevron U.S.A. Inc. in the case of Chevron v. Echazabal, finding that Chevron had the right to deny Echazabel employment in an oil refinery due to a condition caused by Hepatitis C. Chevron had denied Echazabel employment based on the concern that conditions in the oil refinery would exacerbate damage to his liver.<sup>30</sup> This decision implies that the ADA would not be prevented from practicing genetic discrimination in cases where a genetic trait puts the individual at increased risk of work related injury, and so the ADA is unlikely to provide much protection against genetic discrimination.

The Employee Retirement Income Security Act of 1974, (ERISA): This federal law may allow genetic discrimination because it preempts state laws. It provides regulations for employee welfare benefit plans, and was passed to make it easier for national corporations to provide benefit plans to employees in different states. By preempting state laws, ERISA prevents such employers from having to comply with many different state laws, and allows them to follow one set of regulations for employees in many different states. Many states including Rhode Island have passed legislation that protects against genetic discrimination in insurance and employment, and the concern is that these state laws may be preempted by ERISA, allowing genetic discrimination by self-funded employer benefit plans. ERISA does provide one exception to the

preemption rule, and protects the right of states to regulate insurance. ERISA preemptions do not apply to state laws regulating insurance, but employer self-funded health plans might not be considered as insurance. (Large employers often do not purchase group health insurance because their size eliminates the need to pool their risks with other companies, and so they offer a self-funded health plan instead, and pay the cost of treatments themselves.) As long as there is no insurance contract involved in an employer health plan, state law is preempted. This creates difficulties in drafting state legislation, as a significant portion of Rhode Island's population is employed by companies governed by ERISA, <sup>31</sup> and any law attempting to regulate health insurance would not protect these employees.

Pending Legislation: In recent years there have been a number of genetic nondiscrimination laws proposed in the federal congress, such as S.318 introduced by Senator Daschle, H.R. 602 introduced by Representative Slaughter, and S.1995 introduced by Senator Snowe.<sup>32</sup> These bills would prevent health insurers and employers from discrimination based on genetic testing, but would do little to address the current gaps in Rhode Island's legislation. This is because Rhode Island already has comprehensive prohibitions on the use of genetic information in health insurance and employment that go beyond the protections granted in these bills. Further, these bills do not address other forms of insurance in which genetic discrimination is likely occur, such as disability, long term care, or life; and do not provide general protections such as requiring informed consent for collection and analysis of any DNA sample. Most of the proposed federal legislation contains a provision allowing states to pass any law that would further extend protections against genetic discrimination. This means that even if federal legislation is passed, the Rhode Island legislature may still need to reconsider its genetics laws if it is determined in the future there are just uses of genetic information in employment and insurance that are banned by current state law. Although these laws would address several gaps in our legislation by protecting citizens that are employed out of state, employed by companies governed by ERISA, and by granting enforcement powers to the EEOC as S.1995 does<sup>33</sup>; the legislature cannot wait for the federal congress to act and must develop policy to protect against misuses of genetic information regardless of any federal law that is passed.

# Genetic Exceptionalism

This report takes the position that genetic information is unique to other medical information, and therefore deserves special "exceptional" status. Although state and federal legislation already provide for the confidentiality of medical information, genetic information is more sensitive and requires additional privacy protections.<sup>34</sup> An important precedent for granting exceptional status to medical information is HIV policy. In 1988, Rhode Island passed statutes 23-6-10 through 23-6-24, to prevent the spread of the HIV virus and to protect persons infected with HIV from discrimination.<sup>35</sup> These statutes put additional privacy protections on the results of an HIV test, that go beyond the protections placed on normal medical information. Like the results of an HIV test, the results of genetic analysis are more sensitive than other forms of medical information and deserve special protections.

The counter argument to this position holds that genetic information should be protected in the same way as ordinary medical information. If current policy does not have enough protections for genetic information, this means that medical information in general is not protected sufficiently; not that genetic information should be afforded special status.

Information concerning cancers primarily caused by the environment as well as records of psychological impairments can be just as damaging if not more damaging to the individual afflicted as genetic conditions. Why should a women who has been diagnosed with breast cancer that has been linked to the BRCA1 or BRCA2 gene be afforded more protection than a woman who has developed breast cancer that has not been linked a specific gene? Finally, proponents of this view might argue that treating genetic information differently from other medical information might increase the stigma surrounding testing and discourage people from seeking genetic services. Focusing attention on genetic information may foster complacency on the issue of confidentiality of medical information in general.<sup>36</sup>

In response to these claims, it is important to note the many differences between genetic information and all other forms of medical information. There is a major ethical difference between predictive genetic tests, and ordinary diagnostic tests. In the case of the woman who has developed breast cancer that is not linked to any specific gene, it would have been unlikely that she would have experienced discrimination before development of the condition. In the case of the woman who is a carrier of a mutation in the BRCA1 or BRCA2 genes however; it would have been possible to deny employment or insurance well before the condition developed, based on genetic test results alone. Genetic testing differs from ordinary medical testing because of the potential to predict disabling conditions and discriminate against individuals who are completely healthy. Although in many cases, testing will only reveal a predisposition to disease that has no more predictive power than a behavioral factor such as smoking, there are certain cases in which testing reveals a guaranteed outcome. Huntington's Disease for example, will eventually affect every individual that is a carrier of the gene. Another important feature of genetic information is the implications it may have for family members. Any third party that has access to an individual's genetic information will also know something about that individual's family members. In the case of identical twins, any genetic information concerning an individual reveals all of the genetic information concerning that individual's twin. Sometimes family members may not wish to know what genetic conditions they are predisposed to, especially if there is no cure, and it may be impossible to keep the results of one's own genetic test secret if one loses employment or insurance due to test results. Finally, genetic information is permanent and does not change throughout one's life. Unlike predictors of health such as smoking, blood pressure, and weight, there is nothing an individual can do to alter his or her genetic makeup. Information concerning these health-status factors, as well as information concerning acute conditions, lose there predictive power over time; but an individual who tests positive for certain genetic traits may face discrimination for an entire lifetime.

This is not to say that other medical information should not be kept more confidential, but like the results of an HIV test, the results of a genetic test should be afforded higher protection under the law. Genetic information is unique in its potential to predict health outcomes, and this makes it more difficult to justify potential uses by third-parties. For an existing condition it may seem fair in certain situations to deny employment or insurance, but it is less fair however; to discriminate against a perfectly healthy individual on the basis of genetic information, which is highly personal.

# III. Employment

#### Rhode Island Policy

In 1992, Rhode Island passed a bill which created protections against genetic discrimination in the workplace.<sup>37</sup> "Genetic Testing as a condition of Employment," Title 28 – Chapter 6.7, (see appendix), originally prohibited employers, employment agencies, and licensing agencies from requesting, requiring, or administering a genetic test as a condition of employment or licensure. It also prevented these entities from affecting the terms, conditions, or privileges of employment or licensure of any person who obtains a genetic test, and prohibited anyone from selling the results of a genetic test to such entities. This law was amended in 2002 to include additional protections. These new protections prohibit employers, employment agencies, and licensing agencies from affecting the terms of employment or licensure; and from denying an applicant based on an that applicant's decision to obtain a genetic test, refusal to submit to a genetic test, refusal to submit a family health history, refusal to reveal the results of any past genetic testing, or refusal to reveal whether that individual has ever obtained a genetic test. Finally, in addition to all of the protections granted originally, the 2002 amendment prohibits the use of genetic information in general to adversely affect the terms of employment, licensure, or application for employment or licensure, and prohibits the release of genetic information about employees, licensees, or applicants.<sup>38</sup> The terms "genetic information" and "genetic testing" are broadly defined so as to include any relevant information, but specifically exclude standard diagnostic tests administered in a normal medical examination. This law is comprehensive for protecting employees against discrimination in the workplace, with the only gap being enforcement. In addition, it may be necessary in the future to amend this policy if it is determined that there are just uses for genetic information in employment decisions.

Enforcement: This law prohibits all foreseeable misuses of genetic information in employment, but does not effectively ensure that employers will comply. The law provides for the award of punitive and actual damages, and attorney's fees and costs in any civil action brought against a violator. In addition, it provides for injunctive relief against any employer who commits or purposes to commit a violation. These are certainly sufficient penalties and remedies for a violation, but the responsibility to enforce these statutes is placed wholly on the individual, who must take civil action. These remedies may not be sufficient for enforcement, as employees who have been discriminated against may have various reasons for declining to take civil action, such as fear of further discrimination or lack of the resources to file a law suit.

In other areas of discrimination in Rhode Island, such as discrimination based on race, sex, or religion; the Human Rights Commission responds to complaints and conducts investigations. The Commission then recommends a solution, and an administrative hearing is carried out should the parties fail to reach a settlement. These hearings can result in administrative penalties, and the Human Rights Commission can issue the affected individual the right to sue. The Human Rights Commission generally has the responsibility of enforcing Rhode Island's anti-discrimination laws in employment, but it does not however, have jurisdiction over genetic discrimination in employment.

For violations of the Americans With Disabilities Act, the Equal Employment Opportunity Commission investigates complaints and takes civil action. The EEOC then attempts to reach a voluntary resolution between the charging party and the employer, and may sue the employer on behalf of the individual if an agreement cannot be reached. The EEOC may also grant the individual the right to bring civil action without the EEOC's involvement. Workers in Rhode Island have the right to file a complaint with the EEOC, although they are not required to, and do not need the EEOC's permission to sue. The EEOC, however, is a federal agency and is not responsible for enforcing state laws. The EEOC does enforce the ADA, but this federal law may not provide adequate protection against the misuse of genetic information.

Most states require that claimants file an alleged unlawful employment violation with the EEOC, or with an equivalent state agency – which in Rhode Island, happens to be the Human Rights Commission. This is not the case however, for violations of Rhode Island's prohibition on genetic testing. There are important advantages of a policy that would require claimants to go through the Human Rights Commission. Cases of unfair discrimination in employment can easily deteriorate into the employer's word against employee's, without any concrete evidence or witnesses. Investigations conducted by a state agency however, can establish discrimination by evaluating larger samples of employees and examining the employer's treatment of key groups. Also, administrative penalties can be placed on violators in addition to civil remedies, and a suit can be brought against violators on behalf of the individual, who may not have the desire or ability to bring civil action on his own. Granting administrative power to the Human Rights Commission would improve the state's ability to enforce its law against genetic testing, and the legislature should consider this measure.

Future Considerations: This law strongly forbids the use of genetic testing and information in employment decisions. Employers are also prohibited from administering genetic tests, even if the intention is to improve occupational safety. As this technology becomes more sophisticated and more commonly used by the public, it may be necessary to consider exceptions to these prohibitions. Arguments can be made that justice demands genetic testing in situations where the public safety is at stake, where effective treatments exist, and even in cases where the individual's personal safety is compromised.

# Potential Uses of Genetic Testing in Employment

This section outlines the potential reasons that an employer might have for using genetic testing or genetic information to make employment decisions. Some of these reasons seem to be a clear violation of employee rights, while others may be justified.

*Productivity:* Medical examinations and inquiries are permitted under the ADA and state laws because they allow employers to discover existing conditions that may limit an employee's ability to perform essential job functions. The ADA protects an employer's right to deny employment based on an impairment that is job-related and cannot be reasonably accommodated. Genetic testing may allow an employer to predict a future condition or impairment, and deny employment on the basis that it is job-related. In addition, employers may want to save costs by turning down applicants who are likely to become sick if the position calls for an extensive training period, or if the applicant is likely to spend time on sick leave. 40

Occupational Safety: It is the responsibility of the employer to provide a safe work environment, and a technology known as genetic monitoring might be an effective way to do this. Genetic monitoring involves the periodic evaluation of an exposed population, and tests for changes in an individual's genetic material. Chromosome damage can indicate an exposure to radiation or toxic chemicals. 41 "The benefits of a monitoring program include a) identifying a risk for the exposed group as a whole or for individuals; b) targeting work areas for evaluation of safety and health practices; and c) detecting previously unknown hazards – thus possibly decreasing health costs for employers, insurance companies, and society in general."<sup>42</sup> This practice is less controversial than genetic screening and is permitted by Rhode Island law because genetic monitoring is only intended to reveal damage to genetic material, and not heritable traits. Rhode Island law defines genetic testing as "the analysis of an individual's DNA, RNA, chromosomes, proteins and certain metabolites in order to detect heritable diseaserelated genotypes, phenotypes, or karyotypes for clinical purposes."<sup>43</sup> One concern over genetic monitoring is that the resultant action will discriminate unfairly against those workers who have been exposed. Rather than accommodate these workers to prevent future damage, or clean up the work environment to protect all workers, an employer may choose to terminate those who have been exposed in order protect itself from liability should those workers develop a condition from repeated exposure. The Occupational Safety and Health Administration, (OSHA), requires an employer to change the workplace in such an event, but an employer might be able to claim that business necessity prevents this. "Before the use of genetic biomarkers in monitoring workers, a plan should be in place to determine what will happen to workers with results in the extremes of the distribution of results."44 Another issue that needs to be addressed is the question of who has access or should have access to the results of data obtained through genetic monitoring. Presently, genetic monitoring is rarely practiced, but like other genetic technologies, it may become more useful in the future. Policy makers may need to consider certain regulations in order to ensure that this practice improves occupational safety and does not result in an opportunity for genetic discrimination.

Susceptibility Testing: Genetic testing has the potential to determine whether or not an individual is hyper-susceptible to certain toxic substances. An employer may wish to use genetic screening for traits that indicate increased susceptibility for the purpose of denying employment, or in order to accommode individuals that test positive. Employers have an interest in protecting the safety of their workers, and in protecting themselves from liability. An example of susceptibility testing involves beryllium, a metallic element used in nuclear reactors and aerospace design. Exposure to beryllium can cause chronic beryllium disease. Chronic beryllium disease can lead to death, and some individuals are thought to be hyper-susceptible due to their genetic makeup. Although OSHA currently has regulations that limit workers from coming in contact with beryllium, individuals genetically predisposed to beryllium disease may need extra protections. When genetic testing in such cases is used to accommodate workers by moving them to a safer environment or to provide them with additional safety equipment, the employer can protect itself from liability and save lives at the same time. The concern is that employers would use genetic testing in these cases to deny employment or benefits on the grounds that business necessity prevents expensive worker accommodations.<sup>45</sup>

To Deny Worker's Compensation: State law requires employers to cover medical costs and lost wages that result from work-related injuries and illnesses, and employees give up their

right to sue in exchange for this.<sup>46</sup> An employer might attempt to deny workers' compensation on the grounds that the condition was caused entirely by a genetic trait and was not work related. This is exactly what Burlington Northern Santa Fe Railway, (BNSF), was attempting to do until the EEOC filed for preliminary injunction and eventually reached a settlement with BNSF. The railroad company had a nationwide policy of requiring employees who have submitted claims of work-related carpal tunnel syndrome, to provide blood samples in order to test for a Chromosome 17 deletion – which may cause carpal tunnel syndrome in rare cases. Burlington Northern agreed to settle while denying any wrongdoing.<sup>47</sup> This use of genetic testing would be prohibited by Rhode Island law as employers are not permitted to request, require, or administer a genetic test; but employers could make the argument that they should not be held responsible for an illness that is in no way work-related, and that they should have the right to use genetic testing to establish the cause of such an illness.

Public Safety: An employer might use genetic testing or genetic information to deny employment on the grounds that employees with certain genetic conditions pose a risk to the safety of the public or to other employees. This approach is utilitarian in nature, meaning that individual rights are overridden in the interest of the common good. Such a policy could prevent individuals predisposed to a variety of genetic conditions that impair neurological function or motor skills from working a job involving heavy or dangerous machinery, toxic chemicals, public transportation, or any other job on which safety depends on individual job performance. This use of genetic testing would be permitted under the ADA, and such impairments would be considered job-related. Rhode Island law would prohibit genetic testing in this case, and it is possible to make the argument that genetic testing for public safety is unnecessary. Rather than use genetic testing to screen out employees who may develop certain conditions, it might be less discriminatory, and at least at the present time, more cost effective; to simply provide routine medical examinations for employees on which the public safety depends. This is already done for many jobs, and these examinations also identify conditions that are not caused by genetic makeup.

# Policy Options

There are a number of policy options that may be considered in the future to allow for just uses of genetic information and genetic testing in employment decisions. Amendments to our laws may be called for as genetic technologies advance and become more commonplace, and this section outlines possible exceptions to the ban on genetic testing and genetic information in employment. Any exceptions to the ban on genetic testing should only be considered in the context of informed consent, would have to provide for confidentiality, and would require high predictive value and reliability.

Job Related Exceptions: Nine states currently allow employers to use genetic information if the information is job-related and consistent with business necessity, or if it is related to a medical condition that affects occupational qualifications. This option would also cover public safety, as any condition that could jeopardize the public safety or the safety of other workers would necessarily be job-related. Such a policy would be similar to the ADA, which allows exceptions in cases where accommodating the individual is inconsistent with business necessity.

The problem with such a policy, however; is that it might discourage individuals from seeking genetic services because of the fear of losing employment. In addition, such a policy is ethically questionable because it would involve denying employment to individuals who are perfectly healthy on the basis of highly personal information. An alternative may be simply to administer routine medical examinations so that decisions can be made when the condition actually develops. Allowing genetic screening or the use of genetic information would be most justified in order to protect public safety, but even here it may be argued that routine medical examinations would protect safety without violating individual rights.

Susceptibility Exceptions: Allowing employers to test for hyper-susceptibility could protect employers from liability as well prevent illness caused by toxic exposure. In this case, the employee as well as the employer might have a strong interest in the use of genetic information or testing. An employee may carry a "defective gene" which will not express itself until the individual is exposed to an environmental hazard, and a genetic test could prevent a serious illness for that employee. One option would be to allow this sort of testing only in situations where the worker could be accommodated. That way, employees would not have to fear termination, and testing would protect their safety. For situations in which no accommodation can be made, one possible option is to allow voluntary testing. The employer would never have access to the results of the test, and employees could decide for themselves whether or not to risk exposure. This policy could be implemented with or without the provision that employees sign a waiver releasing the employer of liability, should the employee develop an exposure-related illness. The argument for this policy would hold that an employer should not be responsible for paying workers compensation to employees that knowingly put themselves at risk. It is important to consider however, the consequence that this law would have on employees. Any employee who is economically disadvantaged enough to knowingly put himself at risk, is further put at a disadvantage by signing away his right to workers compensation.

#### IV. Insurance

#### Rhode Island Policy

Health Insurance: In 1998, Rhode Island passed legislation that prohibits the use of genetic testing by health insurers. <sup>49</sup> (see appendix.) These laws were amended in 2001 to extend all of the prohibitions on genetic testing to genetic information as well. These laws specifically prevent health insurers from a) releasing genetic information without prior written authorization; b) requesting or requiring the results of a genetic test or genetic information to deny, limit, cancel, refuse to renew, increase the rates of, or affect the conditions of a group or individual health policy, contract, or plan; c) requesting a genetic test or genetic information for the purpose of deciding whether to renew health benefits coverage, to set reimbursement/co-pay levels, or determine covered benefits and services; and d) inquiring as to whether or not an individual has ever had a genetic test. These laws are comprehensive for both group and individual health insurance, and ban every foreseeable misuse of genetic testing in health insurance. A major exception to these protections, however, would be those citizens who obtain coverage from a self-funded employer. Due to ERISA preemptions, Rhode Island's law cannot regulate these benefit plans. (see section II, "Federal Legislation.")

Enforcement: The insurance industry in Rhode Island is overseen by the Department of Business Regulation. Rhode Island law grants this department the power to administer penalties for violations, and suspend or revoke a violator's license. The Department of Business Regulation regularly conducts market conduct examinations of insurance providers, and may conduct an investigation if there is a consumer complaint.<sup>50</sup> In addition to these mechanisms of enforcement, an individual would be able to bring civil action against an insurer. Rhode Island law provides penalties for violators, remedies for those who have been wronged, and places enforcement powers with an appropriate state agency. Enforcement is therefore sufficient for the prohibitions on genetic testing and the use of genetic information in health insurance.

Life, Disability, and Long Term Care Insurance: Rhode Island law **does not** have any protections against genetic discrimination in these areas of insurance. There is potential for the misuse of genetic information in each of these areas, and policy-makers should consider instituting at least some regulation.

# Adverse Selection as an Argument Against Regulation

Adverse selection occurs when individuals have more information about their risk of illness than insurance companies. If this information is likely to influence decision-making in the purchase of insurance, higher risk individuals are likely to purchase more insurance while paying the same price as those at lower risk. To compensate for this, insurers might need to raise premiums across the board, which could limit access to insurance, and discourage individuals at lower risk from entering the market. In the most extreme case, this downward spiral could

eventually lead to the fiscal insolvency of insurance companies.<sup>51</sup> Insurers normally prevent adverse selection by reviewing medical records and in some cases conducting medical examinations, using the information obtained for risk-classification. Individuals at highest risk are charged increased premiums and in extreme cases, may be denied coverage. Insurance companies are concerned that if they do not have access to records of genetic test results, and are prohibited from requesting genetic testing or using genetic information in underwriting decisions, adverse selection is likely to occur.

At the present time it is unlikely that adverse selection due to genetic testing is a significant problem. This is because the technology is limited in its predictive power and because genetic testing is not commonly used. There is much debate as to whether or not adverse selection is likely to be a significant problem with respect to genetic testing. Despite the growing body of economic theory which suggests that an unequal amount of information between insurance applicants and insurance companies can disrupt the function of the insurance market, <sup>52</sup> it can be argued that this is not likely to occur. Adverse selection is only likely to occur if a) there is widespread access to genetic testing, b) the information obtained is likely to influence their policy preferences, and c), individuals have the means to select and purchase more expensive policies.

In addition to these arguments in favor of regulation, it can be argued that allowing insurers to use genetic information in underwriting decisions is unjust because it will prevent those predisposed to genetic diseases from acquiring coverage. Such genetic discrimination could lead to the creation of an entire class of uninsurable people.

The occurrence of adverse selection would provide a strong justification for allowing insurers to use genetic information, but it is unclear to what extent adverse selection is likely to occur. The likelihood of this phenomenon varies across various forms of insurance, and the potential for adverse selection should be considered for each form of insurance respectively, when creating public policy.

Health Insurance: Adverse selection is unlikely to occur in health insurance due to the nature of health insurance policies and the basic need for coverage. Individuals are likely to seek health coverage regardless of whether or not a genetic test has come back positive. In addition, most Americans receive coverage from their employer and do not have the means to select more expensive policies. This can be contrasted with life insurance, where most insurance is purchased in the private market, and individuals have the option of purchasing extremely large policies. Because adverse selection is unlikely to damage the health insurance market, there is little reason to allow health insurers to discriminate based on genetic information. Health care is considered a basic human need, and the public health depends on the accessibility of health services. The use of genetic information in underwriting decisions should therefore be prohibited for health insurers, and Rhode Island's statutes accomplish this.

*Life Insurance:* The potential for adverse selection is greatest within the area of life insurance. <sup>53</sup> Approximately 70% of adults have some form of life insurance, and although some receive it through their employer, approximately three-quarters of all policies are purchased individually. <sup>54</sup> Life insurers typically review medical records and may conduct medical examinations in order to carry out accurate risk classification. It is due to the nature of life insurance that the potential for adverse selection is so much greater here than in health insurance. While individuals are likely to seek adequate health coverage regardless of a positive genetic test

result, an individual is more likely to seek life insurance if he discovers that he is predisposed to a fatal condition. An example of such a gene might be the gene for Huntington's disease, which will eventually kill everyone who carries it. A positive genetic test for the gene which causes Huntington's could significantly affect the amount of money that one is willing to spend on coverage, and denying life insurers the ability to use genetic information could damage the market.

Although most states including Rhode Island do not regulate the use of genetic information in life insurance, insurers rarely request genetic testing due to the high cost and limited utility of the results. Instead they acquire the genetic information needed for risk-classification from family health status records, and in some cases may request the results of previous genetic tests. There is less of a justification for regulating life insurers than for health insurers, but some regulation should be considered to prevent insurers from acting on misinformation. Genetic discrimination is less offensive in this case because life insurance is not considered a basic human need, but some regulation is justified in order to keep the market open to those with less than perfect genes. A bare minimum might be an informed consent policy, so that at the very least, individuals know the meaning and risk of genetic testing before agreeing to submit to testing by an insurer.

Disability Insurance: Disability insurance provides coverage for employees who are unable to work due to an accident or injury. Benefits are provided in the form of an indemnity payment which covers 50 to 70% of an individual's pre-disability income. The potential for adverse selection exists here, but to a lesser extent than in life insurance. This because the individual market comprises only 38% of all policies, and most individuals receive coverage from a group policy. The potential does still exist however, due to the fact that an individuals is more likely to seek disability insurance if a genetic test reveals that he will need it. In addition, disability insurance may not be seen as a basic need in the sense that health care is, and perhaps this is why most states do not regulate the use of genetic information in underwriting decisions. Some regulation may still be needed however, to ensure that this market remains open to those with genetic predispositions to disease. Allowing insurers to use genetic information in this area may effectively deny disability insurance to those who need it most.

Long - Term Care Insurance: Long-term care insurance provides for individuals who are unable to perform the basic activities of daily living without assistance. Services include nursing home care, care at an assisted living facility, hospice care, and a variety of services to promote independent home living. Long-term care is offered in the individual market as well as through employer sponsored group insurance, and as insurance through an association. It is usually offered as a voluntary option through employer sponsored group plans. The potential for adverse selection exists for this form of coverage as in the areas of life and disability insurance. An example for this is Alzheimer's disease, of which an estimated 4 million Americans suffer from. Alzheimer's patients typically live for eight to ten years, and require assistance to perform the basic activities of daily life. Based on this, a positive test result for a gene linked to this disease would be a strong influence in the decision to purchase long-term care insurance. Most states do not restrict the use of genetic information in this area, but some regulation may be needed to insure that those individuals who need long-term care the most, (such as those who suffer from Alzheimer's), are able to get it. In contrast to life insurance, long term care should be considered a basic human need, and is similar to health insurance in that respect.

#### Policy Options

Due to the nature of health care coverage, there should be strong prohibitions on the use of genetic testing and genetic information by insurers, and Rhode Island law establishes these prohibitions. Regulation is less justified in the areas of life, disability, and long-term care insurance; but some restrictions should be considered to ensure that a) these forms of coverage remain open to those who need them most; b) decisions affecting the terms of coverage are not based on misinformation; and c) individuals are not discouraged from seeking genetic services.

Informed Consent: At the very least, the legislature should consider a general informed consent policy for any genetic test required for life, disability, or long-term care insurance. This would insure that individuals being tested would know a) that the test is being done; b) the implications of the results for their health; and c) the potential risk of losing insurability. It might also contain a provision requiring informed consent for the release of genetic information to any third-party. Such a policy would at least protect individuals from being discriminated against without their knowing, and has been adopted by several states. Section V. of this report outlines some of the provisions that might be contained in a general informed consent policy.

Require Actuarial Justification: This option would seek to prevent insurers from acting on the basis of misinformation. It would require insurers to provide a higher standard of credible statistical support that certain genetic predispositions are expected to result in increased insurance claims and represent an unacceptable insurance risk or warrant higher premiums. Such a policy however, may be difficult to enforce and unnecessary. There is a major challenge to obtaining accurate information, as there are many complexities in determining the probability that certain genes will cause illness. For some genes, there are many different mutations that can indicate predisposition to disease; and many diseases are multi-factorial, being caused by a complex interaction of many genes, the environment, and behavior. Further, it may not be necessary to restrict insurers in this way, because it is in their financial interest to obtain accurate information for risk-classification. Still, there is a history of discrimination resulting from insurers being misinformed, and some guidelines may be needed.

Permit Use of Previous Test Results Only: Some states have laws that prohibit life, disability, and long-term care insurers from requesting, requiring, or administering genetic tests, but allow insurers to use the results of previous genetic tests. This kind of policy would prevent genetic discrimination against those who have never obtained a genetic test, while at the same time limiting the possibility of adverse selection. The insurer would in all cases have information similar to that held by the consumer. The problem with this policy however, is that it may discourage individuals from seeking genetic services. An individual aware of the law might choose not to obtain a genetic test out of the fear that the results could be used against him in the future by insurers. In addition, such a policy may not be effective in limiting adverse selection if and when the price of genetic testing comes down. Individuals would be likely to pay for genetic testing out-of-pocket, so as to keep this information out of their medical records. One might even go so far as to give false identification when obtaining a genetic test in order to protect the results.

Safe Harbor: This policy would prohibit insurers from using genetic tests or genetic information up to a certain threshold. A model law drafted by the National Council of Insurance Legislators contains this sort of provision, and bans the use of genetic testing for policies below \$100,000 for life insurance, and for policies below \$60,000 for disability insurance. This approach would seek to limit the affect of adverse selection by allowing insurers to use genetic information for large policies, while providing basic coverage to those who are genetically predisposed to certain diseases. This policy appears to be an acceptable compromise between the interests of insurers and consumers at risk for genetic diseases, and should be considered for life and disability insurance. A major point of debate for this policy will be over where exactly to draw the line. This policy entitles a certain amount of coverage to all regardless of genetic make-up, but there is likely to be disagreement over exactly how much coverage should be guaranteed.

Prohibit the Use of Genetic Testing and Genetic Information: This policy would extend the prohibitions on the use of genetic information in health insurance to other forms of insurance. This policy should not be considered for life and disability insurance, as prohibiting insurers in this way could lead to adverse selection, eventually causing premiums to rise for all. An argument can be made however, to prohibit the use of genetic information for long-term care policies. Long-term care is a form of health care, and HEALTH has an interest in ensuring that long-term care is accessible to all. The legislature should thus consider measures to restrict the use of genetic testing and genetic information for this area of insurance, (that are similar to the measures taken to restrict genetic information in health insurance.)

#### V. Informed Consent

Rhode Island law prevents genetic discrimination in health insurance and employment, but provides little protection against the misuse of genetic information by other third parties. Entities that might have an interest in administering or requiring genetic testing might include life, disability, and long-term care insurers; as well as schools, the Department of Health, adoption agencies, and sperm or blood banks. Although it is unlikely that any of these institutions are currently misusing genetic information, it is difficult to predict the many widespread uses that this technology will have in the future. Paternity testing for example, is a service offered by many commercial laboratories throughout the country. These labs offer "home testing," for which an individual needs only to collect hair samples from the child and potential parent using a "home kit." The individual merely sends these samples to the lab where they are analyzed to determine paternity. Consent is not required from those giving samples, and the results are not admissible in court.<sup>62</sup> This example may not constitute genetic discrimination, but it shows that an individual's DNA can be collected and analyzed without informed consent. A general informed consent policy would help prevent genetic discrimination by requiring written authorization for the collection, analysis, and retention of DNA samples, and for the disclosure of genetic test-results to third parties. Such a policy would protect against unforeseen misuses of genetic testing, and several states have passed laws protecting genetic privacy in general. This policy would not prevent third parties from requiring or using genetic tests, it would merely prevent "secret testing." Institutions may be permitted to use genetic testing in certain circumstances, but at least the individual will know that a test is being administered, will have a basic understanding of the purpose of the test, and will understand the risks involved. Such a policy would be justified on the grounds that genetic information is unique and more sensitive than other forms of medical information, and therefore deserves special protections under the law.

# Provisions of a General Informed Consent Law

A number of states have enacted laws to protect genetic privacy in general, and four states have gone as far as to define genetic information as personal property.<sup>64</sup> These laws have been influenced by model legislation such as the Genetic Privacy Act, which was written in 1995, and outlines an informed consent policy for genetic testing as well as other privacy protections. State laws vary in degree, and include at least some of the following provisions.

Collection of DNA Samples: An informed consent policy would require written authorization for the collection of any individually identifiable DNA sample for the purpose of genetic analysis. The person or institution requesting the sample would be required to inform the individual of the following:

- 1. That consent to the collection and analysis of the sample is voluntary.
- 2. The information that can be expected to be derived from genetic analysis.

- 3. The use that the individual will be able to make of the information derived from genetic analysis.
- 4. The right of the individual to inspect records that contain information derived from genetic analysis.
- 5. The right to have the DNA sample destroyed.
- 6. The right to revoke consent to genetic analysis at any time prior to completion of the test.
- 7. That genetic testing may reveal information about family members.
- 8. That third parties may request the results of the genetic analysis and condition a benefit on the release of this information.
- 9. The protections provided by the law concerning the collection and analysis of the DNA sample, as well as the protections of test results.
- 10. Of the availability of genetic testing.<sup>65</sup>

This would ensure that anyone submitting to a genetic analysis would have at least a basic understanding of the fact that a genetic analysis is being conducted, the purposes of the analysis, the risks and benefits of the analysis, and the privacy rights that are granted to the individual by law.

Analysis of DNA Samples: Genetic testing of individually identifiable DNA would be prohibited, and any laboratory conducting a genetic test would have to ascertain that written authorization has been obtained from the individual. Assuring that laboratories are abiding by this provision, as well as quality assurance in general of labs that are conducting genetic tests, may be the responsibility of the Department of Health. According to the Secretary's Advisory Committee on Genetic Testing of the NIH, state health agencies have an oversight role in genetic testing, which includes the licensure of personnel and facilities that perform genetic tests. 66

Disclosure of Genetic Information: In order to disclose the results of a genetic test to any third party, written authorization would be required. This provision may also be expanded to protect other forms of genetic information. It would require that the individual be informed as to who is receiving the information, the nature of the information being disclosed, and the purpose for which the disclosure is being made. Notification would be required to the individual for each disclosure of genetic test results. This would prevent third parties from accessing existing genetic information or the results of a genetic test without the individual's knowledge or consent.<sup>67</sup>

Property Rights: At the present time, four states define genetic information as personal property. This grants the individual the right to order the destruction of the DNA sample at any time, but could have other unforeseen consequences. Oregon's Genetic Privacy Act, which was passed in 1995, originally contained such a provision in order to grant the individual a larger degree of control over genetic information. Opponents have argued however; that such property rights could have unintended consequences for the pharmaceutical and biotechnology industries. These rights could potentially hinder research and discourage private investment by potentially giving rise to claims by research subjects on newly developed drugs and procedures. The Oregon Genetics Research Advisory Committee examined the issued and reported in 2000 that "it is not essential to retain the property clause" and that genetic privacy could better be protected

through strong informed consent provisions for genetic testing and stiff civil remedies and criminal penalties for violations. The Oregon legislature responded by repealing the property rights provision in 2001.<sup>70</sup> While defining genetic information as the property of the individual may be too strong a measure, granting an individual the right to order the destruction of a DNA sample may be a necessary protection of privacy. One option might be to grant this right only in cases where a sample is identifiable, and allow institutions to retain samples and information so long as they are anonymous. This would allow protection of privacy, and would avoid the difficulties for scientific research that might result from defining genetic information as the individual's property.

*Exceptions:* Genetic testing or the release of genetic information could be permitted in certain circumstances without the informed consent of the individual. These circumstances may already be governed by other statutes, and need not be addressed by new legislation concerning informed consent. Such exceptions include law enforcement, and court-ordered paternity testing.

The Department of Health, Newborn Screening, and Population Screening: Newborn screening may or may not be considered as an exception to a general informed consent policy. Newborn screening may be considered an exception to informed consent based on the fact that this practice saves lives and does not violate privacy, (so long as testing is only carried out for conditions that are treatable, and identifiable samples are not released to third parties in the future.) Newborns are incapable of expressing consent, and it can be presumed that if given the choice, they would opt to be screened for genetic diseases that are life threatening and can be treated. Thus, it may not be ethically necessary to obtain written authorization.

Rhode Island currently allows parents to turn down newborn screening for religious reasons. This right may not be valuable to the individual without an informed consent policy, however; because without such a policy, the individual may not know that this right exists. Informed consent is not currently required for newborn screening. Rhode Island law<sup>71</sup> grants the Department the power to regulate newborn screening, and the development of an informed consent policy should be considered.

This issue will need to be addressed in the broader context when population based genetic screening becomes a reality. This issue presents a challenge for the department, as informed consent may hinder HEALTH's pursuit of its mission. On the one hand, requiring informed consent might help educate the public about genetic services and assure people that their privacy will be protected; but on the other, it seems that a consent form might lead people into rejecting newborn and population based screening in cases where they might not have thought twice about it. Rather than take the risk that the public will not give consent, it may make more sense to simply develop and publicize a policy on the protection of the samples and genetic information obtained from screening programs. Informed consent is only necessary in situations where an individual's information can be misused, and so it may not be necessary for the department to obtain informed consent, so long as HEALTH places strong enough protections on the information it obtains. The goal is to obtain the health benefits that can be realized through newborn and population screening, without violating individual rights in such a way that discourages the public from seeking genetic services. Policy makers will need to carefully balance the public good with individual rights.

Enforcement: There are many difficulties for the implementation and enforcement of a policy such as this. One option might be to place the responsibility entirely on the individual to bring civil action against violators, but this may not be effective given the fact that an individual may be able to prove that genetic information has been used against them. Rhode Island might consider fines for violations, and even criminal penalties. Oregon's Genetic Privacy Act grants the Attorney General and District Attorneys the power to bring an action against violators, and makes certain violations misdemeanors, subject to criminal penalty.<sup>72</sup> Criminal penalties however, may be too drastic and are probably not appropriate for violations of this nature.

Because there are variety of different entities that might violate this policy, it would be difficult for any one government agency to oversee and examine regulated institutions, in the same way that the Department of Business Regulation oversees the use of genetic testing in health insurance. A more effective approach might be to focus on the laboratories which are conducting genetic analyses, to insure that they have ascertained the informed consent of those individuals whose DNA is being tested.

#### HIV Testing as a Precedent

In 1998, the Rhode Island General Assembly enacted legislation to protect individuals infected with HIV from discrimination.<sup>73</sup> This law takes the position that HIV status is exceptional to other forms of medical information, and deserves extra protections under the law. Section 23-6-22 addresses discrimination specifically, and states that no person, agency, organization, or corporate body may discriminate against a person on the basis of an HIV test result, or perception of a positive test result, in housing, employment, credit, public accommodation, or delivery of services. An HIV test may only be required as a condition of employment in cases where competent medical authorities are willing to testify that there is a clear and present danger of HIV transmission to others. The use of HIV status by health insurers is restricted, while it is permitted in life insurance in order to counter adverse selection. This law requires informed consent for HIV testing in any case where the result will be identifiable, and charges the Department of Health with standardizing the consent form. Written authorization is also required for the disclosure of test results, and the individual has the right to bring civil action against violators. Section 23-6-14 outlines the many exceptions to these protections, but informed consent is generally required in order to perform an HIV test and to release the results. This law establishes a precedent for exceptional medical information; and it can be argued that genetic information, like HIV status, should be protected above other medical information with an informed consent policy. Just as the results of an HIV test can be used by third parties such as employers and insurers to deny benefits, can have consequences for one's family members, and can be socially stigmatizing; so can the results of a genetic adversely affect an individual. Like HIV status, genetic information is unique and more sensitive to other medical information, and a general informed consent policy should be considered.

# VI. Conclusion

Rhode Island's laws are comprehensive for protecting against genetic discrimination in the areas of employment and health insurance, however; they lack penalties and enforcement powers for the employment statute. This is because the responsibility lies entirely on the individual to bring civil action against an employer and an employee may have various reasons for not taking such action. I recommend that the Human Rights Commission be given jurisdiction over genetic testing in employment. This will make it easier for individuals who have been discriminated against to recover damages, and improve the likelihood that the prohibition of genetic testing will be enforced.

Other considerations for the area of employment include the possibility of permitting genetic testing in certain situations. Policy will have to carefully drafted so that only fair uses of genetic testing are permitted. Once such use would be administering genetic tests, but requiring that employees testing positive be accommodated and not denied benefits. Another fair use would be administering genetic tests in cases where the public safety is at issue, and routine medical examinations are inadequate for ensuring the health of the employee. An example of this would be the airline industry, where pilots might be screened for genetic traits that impair motor skills. Finally, it would also be just to allow employers to offer voluntary testing for hyper-susceptibility to toxic chemicals, as long as the terms of employment are not affected by test results or the decision to refrain from testing. These exceptions to the ban on genetic testing in employment should be considered in the future, as improvements in genetic technology make them feasible.

While Rhode Island's laws provide adequate protections against the misuse of genetic information by health insurers, there are no regulatory protections in the areas of disability, life, and long-term care insurance. This lack of regulation may be justified on the grounds that adverse selection could upset these markets as genetic testing becomes more common, but some regulation is needed in order to keep access to these forms of insurance open to those who need them. There are various policy options for accomplishing this, which should be considered before genetic discrimination in insurance discourages people from seeking genetic services. For life and disability insurance, the "Safe Harbor" option is recommended. This option would prevent adverse selection by allowing insurers to use genetic information or require genetic testing for policies that pay large benefits, but would allow everyone access to more basic coverage by banning the use of genetic information for modest policies. This policy option is less applicable to long-term care insurance, due to the nature of the benefits. A ban on genetic testing and the use of genetic information should be considered here, given that long-term care is a form of health care.

There are many other institutions that will potentially seek and misuse genetic information, and it is difficult to foresee where genetic discrimination may occur in the future. In order to protect against this, the General Assembly should consider a general informed consent law. Such a law would require written authorization for the collection, analysis, and retention of a DNA sample, as well as for any disclosure of genetic test results. This would ensure that those being tested would have at least a basic understanding of the potential risks and benefits of testing, the fact that testing is being done, and of their rights.

Genetic discrimination is not currently a widespread problem, as the cost and limited predictive power of genetic testing make it economically unfeasible. Both of these factors can be

expected to change however; as scientific research will undoubtedly reduce the cost of existing genetic tests, and make new and more powerful tests available. Sound public policy is needed to ensure that the many goods which can be obtained through the use of this technology do not come at the cost of individual privacy rights. Adequate protections against genetic discrimination are needed not only because justice demands them, but in order to encourage people to utilize new and promising genetic technologies.

# Appendix. Rhode Island's Laws Regarding Genetic Testing<sup>74,75</sup>

#### Title 28 – Chapter 6.7 – **Genetic Testing as a condition of Employment:**

This statute was created in 1992 to protect employees from discrimination based on genetic testing. It was amended in 2002 to prohibit employers from discriminating on the basis of genetic information, from forcing employees to reveal whether they have ever had a genetic test before, and the results of any test that the individual may have previously taken. The 2002 amendment also prohibits employers from releasing genetic information, and provides a more comprehensive definition of genetic testing.

mation, and provides a more comprehensive definition of genetic testing.		
	States that no employer, employment agency, or licensing agency may request,	
	require, or administer a genetic test to any employee, licensee, or applicant for	
	employment or licensure. They are also prohibited from affecting the terms of	
	employment or licensure or denying employment or licensure to any person who	
	obtains a genetic test, who refuses to submit to a genetic test, refuses to submit a	
	family health history, or refuses to reveal whether or not they have ever had a	
	genetic test and what the results may have been. In addition, it prohibits the use	
	of genetic information to adversely affect the terms of employment, licensure, or	
	application for employment or licensure; and prohibits the release of genetic	
	information about employees, licensees, or applicants. Finally, it prohibits	
	anyone from selling the results of a genetic test to an employer, employment	
	agency, or licensing agency.	

28-6.7-2	Defines Genetic Testing. (This section was repealed in 2002.)
28-6.7-2.1	Definitions. (This section was added in 2002, and provides a more
	comprehensive definition of genetic testing as well as additional definitions.)
28-6.7-3	Describes penalties.
28-67-4	Describes Severability

Prohibits Waiver. (This section was added in 2002, and declares any contract that purports to waive the provisions of this chapter as null and void.)

#### Title 27 – **Insurance:**

28-6.7-1:

Genetic Testing: The following statutes relate to health insurance, and were created in 1998 to prohibit the use of genetic testing by accident and sickness insurance policies, nonprofit hospital service corporations, nonprofit medical service corporations, and health maintenance organizations. These providers are prohibited from releasing genetic information without prior written authorization of the individual and from requesting or requiring the results of a genetic test to deny, limit, cancel, refuse to renew, increase the rates of, or affect the conditions of a group or individual's health policy, contract, or plan. They are also prohibited from requesting a genetic test for the purpose of deciding whether to renew health benefits coverage, to set reimbursement /co-pay levels, or determine covered benefits and services. Finally, they are also prohibited from requesting information as to whether or not an individual has ever had a genetic test.

*Genetic Information*: In 2001 these sections were amended to extend all of the restrictions regarding genetic testing to include genetic information in general.

Chapter 18: Accident and Sickness Insurance Policies

27-18-52 Genetic Testing.
27-18-52.1 Genetic Information.

27-18-3.3 Penalties for violations of 27-18.

Chapter 19: Nonprofit Hospital Service Corporations

27-19-44	Genetic Testing.
27-19-44.1	Genetic Information.
27-19-39	Allows medical providers to bring civil action against violators of chapter 27-19.
Chapter 20: No	nprofit Medical Service Corporations
27-20-39	Genetic Testing.
27-20-39.1	Genetic Information.
27-20-34	Allows medical providers to bring civil action against violators of chapter 27-20.
Chapter 41: He	alth Maintenance Organizations
27-41-53	Genetic Testing.
27-41-53.1	Genetic Information.
27-41-17	Provides for suspension or revocation of license for an HMO that has violated
	chapter 27-41.
27-41-21	Describes administrative penalties for violations of chapter 27-41.
27-41-48	Allows medical providers to bring civil action against violators of chapter 27-41.

HIPPA: In 2000, the following two chapters were created in order to insure compliance of all policies, contracts, certificates, and agreements of individual health insurance coverage offered or delivered in Rhode Island with the Health Insurance Portability and Accountability Act of 1996, (HIPPA.) ~ (hyperlink to federal legislation section. http://www.health.state.ri.us/genetics/insurance.htm#federal)

#### Chapter 18.5 – Individual Health Insurance Coverage

. . .

27-18.5-2 States that genetic information shall not be treated as a preexisting condition in the absence of a diagnosis of the condition related to that information.

#### Chapter 18.6 – Large Group Health Insurance Coverage

27-18.6-3 Limitations on preexisting condition exclusion: States that genetic information shall not be treated as a preexisting condition in the absence of a diagnosis of the condition related to that information.

#### Chapter 50 – Small Employer Health Insurance Availability Act

This chapter was originally passed in 1992 to enhance the availability of health insurance coverage to small employers regardless of health status or claims experience. It was amended in 2000, and now states that genetic information shall not be treated as a preexisting condition in the absence of a diagnosis of the condition related to the information. It effectively prohibits insurers from denying coverage or affecting the terms of any policy offered to small employers based on genetic information.

27-50-3 Definitions: States that genetic information shall not be treated as a preexisting condition in the absence of a diagnosis of the condition related to the information.

*Oversight*: The Dept. of Business Regulation is responsible for enforcing Title 27 and has the power to impose penalties for violations.

#### Title 42 – Chapter 14 – **Department of Business Regulation**

Insurance – Administrative penalties: This statute grants general administrative powers to the Director of the Dept. of Business Regulation for enforcement of Title 27.

#### Title 27 – Chapter 29 – **Unfair Competition and Practices**

Cease and desist orders and modifications thereof: Grants the insurance commissioner administrative powers against insurers engaging in unfair competition and practices.

#### Title 23 – Chapter 13 – Section 14 – **Newborn Screening Program:**

Requires that physicians screen newborn children for metabolic, endocrine, and hemoglobinopathy disorders, and that the department of health make rules and regulations pertaining to metabolic disease screening, diagnostic, and treatment services. The department of health is authorized to establish by rule and regulation a reasonable fee structure for the newborn screening and disease control program. In addition, this statute states that its provisions shall not apply if the parents of the newborn object to such tests on the grounds that the tests conflict with religious tenets and practices. This statute was enacted in 1987 in addition to 23-13-15, which created a newborn sickle-cell disease testing program. The original statute created a newborn metabolic disease testing program that would be paid for by the hospital or facility in which the birth took place. An amendment was enacted in 1988, and this statute now states that the program is a covered benefit, reimbursable by all health insurers. It was amended in 1995 to include endocrine and hemoglobinopathy disorders, and was renamed the newborn metabolic disease control program. This statute was amended again in 2001 to provide for screening tests specifically, and renamed as the newborn screening program. The 2001 amendment also repealed 23-13-15, eliminating the sickle-cell disease screening program, as screening for this disorder is included in the newborn screening program.

#### Title 10 – Chapter 9.1 – **Post Conviction Remedy**:

This chapter describes post conviction remedy and was amended in 2002 to include the following statutes which provide for DNA testing as a remedy for post conviction relief. They set out guidelines for the preservation of biological evidence post conviction, and allow any person convicted of a crime and who is currently serving a term of imprisonment to petition the superior court requesting the forensic DNA testing of such evidence. It requires mandatory DNA testing in cases where a reasonable probability exists that the individual would not have been prosecuted or convicted if exculpatory results had been obtained through DNA testing. Further, it allows the superior court to order DNA testing if a reasonable probability exists that the required testing will produce results which would have altered the verdict or reduced the individual's sentence, had such results been available prior to the proceedings leading to the conviction

10-9.1-10	Definitions.
10-9.1-11	Mandatory Preservation.
10-9.1-12	Testing: Mandatory and Discretionary.

#### Title 12 – Chapter 1.5 – **DNA Detection of Felony Offenders:**

Establishes a state DNA databank and DNA database containing DNA samples and DNA records of individuals convicted of a crime of violence as defined in 11-47-2, and missing persons. This statute was created in 1998 and originally required obtaining DNA samples from individuals convicted of certain sexual and violent offenses, and missing persons. It was amended in 2001 and now requires testing of any individual convicted of a crime of violence as defined in 11-47-2 and missing persons.

12-1.5-1	Policy. (Describes the purpose of this law, and was amended in 2001 to include
	any crime of violence as described in 11-47-2.)
12-1.5-2	Definitions.
12-1.5-3	Powers and duties of the department of health.
12-1.5-4	State DNA database.
12-1.5-5	State DNA databank.
12-1.5-6	Procedural compatibility with FBI.
12-1.5-7	Scope and applicability. (Amended in 2001 to include any crime of violence for
	offenses committed after July 1, 2001.)
12-1.5-8	DNA sample required upon conviction.
12-1.5-9	Procedures for withdrawal, collection and transmission of DNA samples.
12-1.5-10	Procedures for conduct, disposition and use of DNA analysis.

12-1.5-11	DNA database exchange.
12-1.5-12	Authority to cancel access to or exchange of DNA records.
12-1.5-13	Expungement.
12-1.5-14	Prohibition and disclosure.
12-1.5-15	Criminal penalties – Civil Remedies.
12-1.5-16	Confidentiality of records.
12-1.5-17	Convicted persons – Refusal to give DNA sample.
12-1.5-18	Interpretation and severability.

# Title 15 – Chapter 8 – **Uniform Law on Paternity:**

# 15-8-11 – Parentage Tests:

Allows courts to use DNA testing to establish paternal identity. This statute was created in 1984, and originally provided for genetic testing as well as blood or tissue typing tests as a method for determining paternity. It was amended in 1996 to include DNA testing specifically.

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<sup>&</sup>lt;sup>2</sup> Scott Burris, Lawrence O. Gostin, and Deborah Tress, "Genetics and Public Health: Ethical, Legal, and Social Issues," in *Genetics and Public Health in the 21<sup>st</sup> Century*, presented online at the Centers for Disease Control and Prevention, (CDC), Office of Genomics and Disease Prevention Web site, (<a href="www.cdc.gov/genomics/info/books/21stcent5.htm">www.cdc.gov/genomics/info/books/21stcent5.htm</a>); 1.

<sup>&</sup>lt;sup>3</sup> Rhode Island Department of Health, *Rhode Island State Genetics Plan*, Aug. 2001.

<sup>&</sup>lt;sup>4</sup> Secretary's Advisory Committee on Genetic Testing, (SACGT), *Components of Genetic Services*, Distributed at SACGT Town Meeting on Disparities in Access to Genetic Services, July 11, 2002, during the National Leadership Summit on Eliminating Racial and Ethnic Disparities in Health.

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<sup>&</sup>lt;sup>10</sup> Centers for Disease Control, *Recognizing the Opportunities, Identifying Barriers, and Meeting the Challenges of Genomics and Public Health*, a fact sheet presented online at the Centers for Disease Control and Prevention, (CDC), Office of Genomics and Disease Prevention Web site, www.cdc.gov/genomics/info/factshts/opportunity.htm.

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<sup>&</sup>lt;sup>12</sup> Ruth Hubbard and Elijah Wald, *Exploding the Gene Myth*, (Boston Massachusetts: Beacon Press, 1993); 34.

<sup>&</sup>lt;sup>13</sup> CDC, Recognizing the Opportunities, Identifying Barriers, and Meeting the Challenges of Genomics and Public Health.

<sup>&</sup>lt;sup>14</sup> Hubbard and Wald, 34.

<sup>&</sup>lt;sup>15</sup> Testimony of Francis S. Collins, M.D., Ph.D., Director, National Human Genome Research Institute, before the Committee on Labor and Human Resources, United States Senate, May 21, 1998, Department of Health and Human Services, (<a href="https://www.hhs.gov/asl/testify/t980521a.html">www.hhs.gov/asl/testify/t980521a.html</a>); 3.

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